

McArdle disease: When to seek urgent medical attention

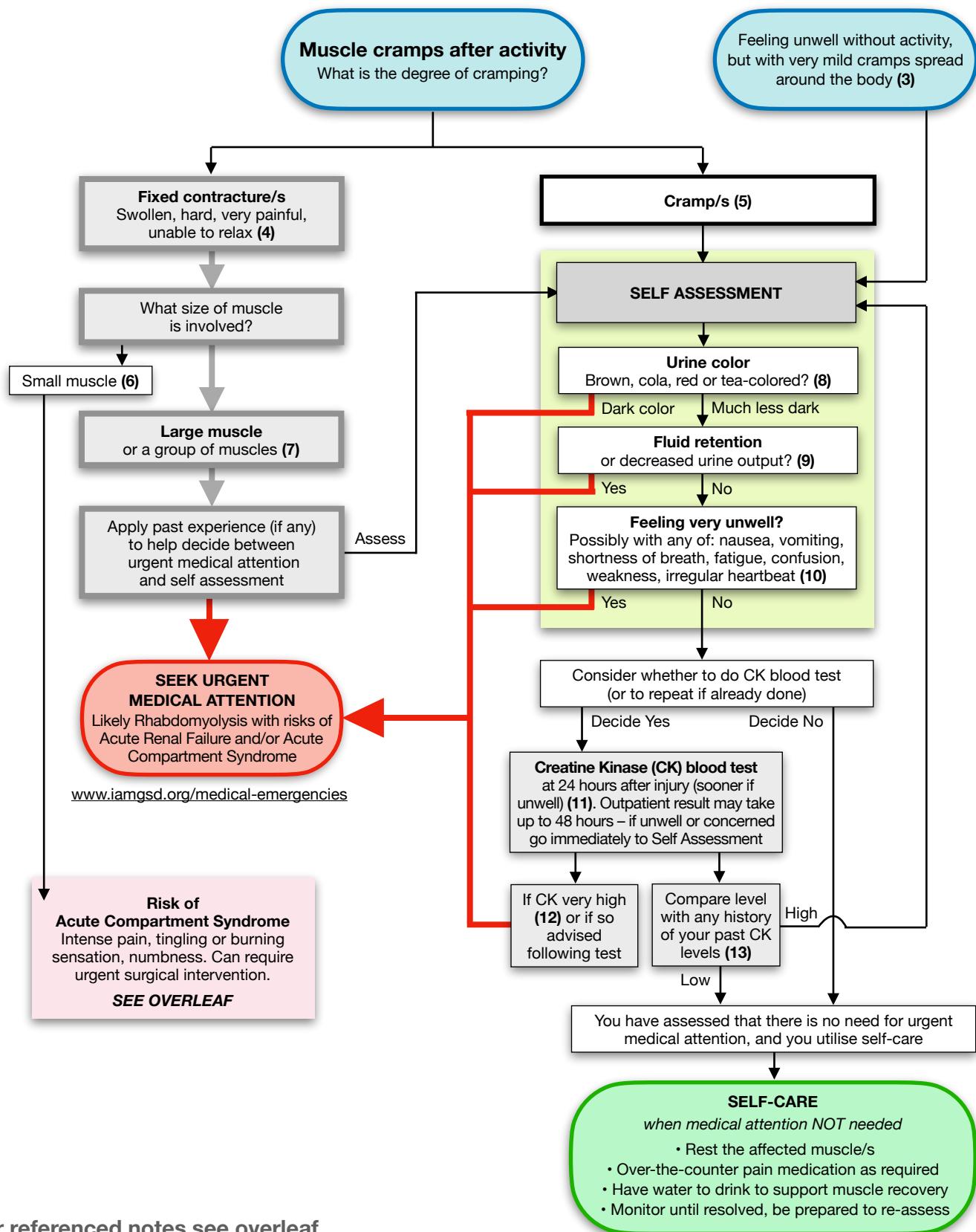
(This guidance is likely to also apply to the other muscle GSDs covered by IAMGSD.)

Guidance to assist you in deciding whether to seek urgent medical attention

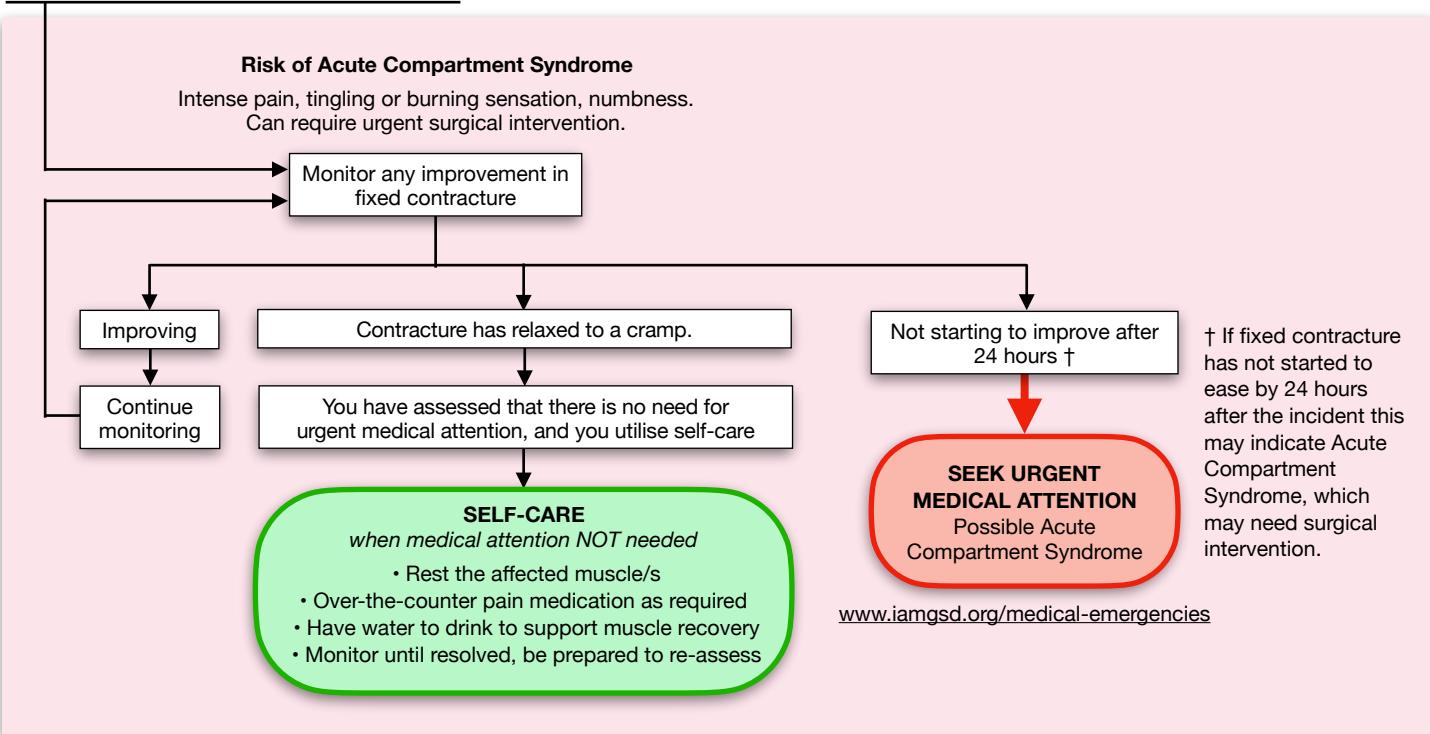
Each person with McArdle disease is an individual (1). However, this flowchart gives general guidance on how the individual can assess their need for urgent medical attention in the event of a bad episode.

Start at one of the two blue boxes. If required, you may be able to confer by phone with your McArdle's consultant, specialist nurse, or GP.

These assessments are subjective. If in any doubt use caution and seek urgent medical attention (2).



For referenced notes see overleaf



NOTES TO THE FLOWCART OVERLEAF

- (1) Other medical conditions, sensitivity to pain, kidney function, etc can all vary between people.
- (2) Acute Renal Failure is very serious and can be fatal. Acute Compartment Syndrome can require surgical intervention to relieve pressure, or even surgical removal of the muscle.
- (3) A very small percentage of McArdle's episodes appear to be caused by stress and tense muscles rather than by excess activity.
- (4) Fixed muscle contractures in large muscles or groups of muscles are the most common cause of needing urgent medical attention.
- (5) Cramps which typically recover in about an hour or less, do not require further investigation.
- (6) For example: in muscles under the forearm used when gripping, a fixed contracture causes "the claw". Small muscles are very unlikely to release sufficient breakdown products to cause acute renal failure, but may develop acute compartment syndrome. (Large muscles can also develop acute compartment syndrome, but this can be monitored along with the rhabdomyolysis.)
- (7) Large muscles, for example in the thighs and back, or groups of muscles, such as in a limb, are typical sites for severe episodes.
- (8) Urine color can be affected by many factors. If cola-colored or dark red or close to these, this is likely to be from myoglobin and urgent medical attention is warranted.
- (9) Urine output significantly below fluid input across 24 hours may indicate acute renal failure.
- (10) Feeling very unwell with any of these symptoms may indicate acute renal failure.
- (11) The CK (also known as CPK) level tends to peak at 24 hours after the incident/injury, then reduces at approx. 30% to 50% per 24 hours.
- (12) As an approx. guide, levels over 20,000 IU/L are very likely to need urgent medical attention, but some people may need attention below that figure.
- (13) If available, compare to your baseline figure (average in McArdle's is around 2500 IU/L) and your levels reached in any previous episodes.